

Chapter VI. Diabetes and Other Chronic Disabling Conditions

Introduction. Chronic disabling conditions surround us. One quarter of all Americans provide some degree of personal care for the 35 million among us who live with a chronic health condition such as diabetes, cancer, asthma, heart disease, muscular dystrophy, AIDS, dementia, alcoholism, or injuries that cause disability.

In 1995, an estimated 99 million people in the United States had chronic conditions characterized by persistent and recurring health consequences lasting for periods of years. Of these, 41 million were limited in their daily activities by their chronic conditions. Twelve million of those were unable to go to school, to work, or to live independently. As the American population ages, the number of people with chronic conditions will increase dramatically. It is estimated that by 2030, 150 million Americans will have a chronic condition; 42 million of those will be limited in their ability to go to school, to work, or to live independently.

Providing adequate services for people with chronic conditions has significant implications for national health care expenditures. In 1990, \$470 billion was spent on the direct costs of medical services for persons with chronic conditions, including nursing homes and other institutional care. This does not take into account indirect costs for lost of productivity or socio-psychological costs associated with people who have chronic conditions.

The health care delivery system will have to continually evolve to address the need for cost-effective, coordinated health care for the growing number of Americans who have chronic health conditions. The financial incentive inherent in the traditional fee-for-service health care system do not necessarily encourage appropriate types of care for people with chronic conditions. In comparison with acute conditions, chronic conditions call for a different kind of care: an integrated network of professional expertise, and a far greater reliance on nonprofessional and informal caregiving – that is, on family, friends, and community-level organizations.

The goal of chronic care is not to cure; rather, it should help individuals with chronic conditions maintain independence and a high level of functioning. This chapter will look at three specific chronic conditions, diabetes, asthma, and Alzheimer's disease and ways in which to reduce the effects of the disease and prolong health related quality life.

· Part 1. Diabetes

A. Overview

Diabetes is a major cause of disability and death in Hawai`i, as it is nationally and throughout the world. Since age and ethnicity are major risk factors for diabetes, prevalence is high in Hawai`i. Our population is getting older, and people of Hawaiian, Polynesian and other Pacific Island ethnic background, who make up approximately 20% of our unique community, are at high risk for developing diabetes.

Diabetes is a chronic disabling disease in which the body does not produce or properly use insulin, which is a hormone needed to convert sugar, starches, and other food into energy required to support life functions. Consequently, people who have this disease have higher than normal levels of sugar in their blood stream. The cause of the disease is unknown. However, it does appear that genetic, lifestyle, and environmental factors play a major role in developing the disease. At this time, there is no known cure for diabetes.

There are two major types of diabetes:

- **Diabetes Mellitus 1.** People who suffer from this type of diabetes produce little or no insulin. These people must take daily injections of insulin in order to stay alive. Type 1 diabetes most often occurs in children and young adults and accounts for approximately 5-10% of all diabetes cases.
- **Diabetes Mellitus 2.** This is the most common form of diabetes. It affects mostly adults over the age of 40. For people who suffer from this type of diabetes, their bodies either do not produce enough insulin or do not properly utilize insulin, which results in a metabolic disorder that may require major lifestyle changes, medications, or insulin injections. Type 2 diabetes accounts for 90-95% of all cases and is approaching near epidemic proportions as the population ages.

There is also a diabetes-like condition called Impaired Glucose Tolerance (IGT) in which the body's blood sugar levels are higher than normal but not high enough to be classified as Diabetes 2. Approximately 40-45% of persons age 65 and older have either Diabetes 2 or IGT.

The American Diabetes Association characterizes diabetes as a "silent killer" because many affected people are unaware that they have the disease until they develop one or more of its life-threatening complications:

- **Blindness.** Diabetes is the leading cause of blindness for people ages 20-74.
- **Kidney Disease.** 10-20% of people with diabetes develops kidney disease. For many diabetics with kidney disease, their condition gradually deteriorates into out-right kidney failure, or End Stage Renal Disease (ESRD).
- **Nerve Disease and Amputations.** Approximately 60-70% of people with diabetes suffers from some form of nerve damage, which in severe cases can lead to lower limb amputation. Diabetes is the most frequent cause of non-traumatic lower limb

amputations. People with diabetes are 15-40 times more likely to experience a limb amputation than those without diabetes.

- **Heart Disease and Stroke.** Heart disease is present in nearly 75% of all diabetes-related deaths. People with diabetes are 2-4 times more likely to suffer a stroke or develop cardiovascular disease.

The major risk factor for Diabetes Mellitus 1 is genetic. Siblings of people with Diabetes 1 and children of parents with Diabetes 1 are at very high risk for the disease. The major risk factors for Diabetes Mellitus 2 are:

- Family history of diabetes
- Being more than 20% over one's ideal weight
- Lack of regular exercise
- Ethnicity: Asians, Hawaiians, Pacific Islanders, Filipinos, African Americans, Hispanics, and Native Americans are at higher risk of developing the disease than other ethnic groups.
- Women who experienced diabetes-like conditions during pregnancy (gestational diabetes).

Warning Signs – Symptoms of Diabetes:

Diabetes Mellitus 1

Frequent Urination
Unusual Thirst
Extreme Hunger
Extreme Fatigue
Irritability
Frequent Nausea
Unusual Weight Loss

Diabetes Mellitus 2

Any Diabetes Mellitus I symptom
Frequent Infections
Blurred Vision
Abrasions That Are Slow to Heal
Tingling/Numbness in the Hands or Feet
Recurring Skin, Gum or Bladder Infections

Diabetes is one of the most costly health problems in Hawai'i. Health care and related treatment costs, as well as the opportunity cost of lost productivity, can be conservatively estimated to run approximately \$400 million annually (based on national estimates). On top of this, there are high socio-psychological costs associated with diabetes, which are difficult to quantify in economic terms. As the health of our diabetic people deteriorates over time, they become more and more dependent on treatment and the help of others, and at the same time less and less mobile. Consequently, their quality of life and self-esteem suffer tremendously. We cannot put a price tag on the psychological costs of diabetes.

B. Measures/Indicators

1. Process Measures

The matrix below identifies key process measures and indicators that are pertinent to achieving the Hawai'i's Health People 2000 goals for reducing diabetes-related deaths.

Measure Number	Monitor	Definition	Guideline	Hawai'i Experience	Guideline/ Hawai'i Experience Source	Cross-Reference
CDP-D1	Number of Diabetes Screening Programs		To Be Updated By SHCC's PDC	To Be Updated By SHCC's PDC		<i>Maternal, Infant and Child Health</i>
CDP-D2	Glycosolated Hemoglobin Test Results		To Be Updated By SHCC's PDC	To Be Updated By SHCC's PDC		
CDP-D3	Diabetic Foot Exam Rate		To Be Updated By SHCC's PDC	To Be Updated By SHCC's PDC		
CDP-D4	Diabetic Eye Exam Rate		To Be Updated By SHCC's PDC	To Be Updated By SHCC's PDC		
CDP-D5	Dialysis Rate		To Be Updated By SHCC's PDC	To Be Updated By SHCC's PDC		
CDP-6	Patient Education or Diabetes Management Programs	Number of diabetics enrolled.	To Be Updated By SHCC's PDC	To Be Updated By SHCC's PDC		<i>Maternal, Infant and Child Health, Behavioral Health</i>

2. Outcome Measures

The matrix below identifies key outcome measures and indicators that are pertinent to achieving the Hawai'i's Health People 2000 goals for reducing diabetes-related deaths.

Measure	Monitor	Definition	Guideline	Hawai'i	Guideline/	Cross-
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Number				Experience	Hawai'i Experience Source	Reference
CDO-D1	Diabetes Prevalence Rate	Number of Diabetics per 1000 persons	29.6 (National) 20.0 (Healthy Hawaii 2000 Goal)	43.8	1996 study in Hawaii	<i>Maternal, Infant and Child Health</i>
CDO-D2	Diabetic-Related Inpatient Admission Rate		To Be Updated By SHCC's PDC	To Be Updated By SHCC's PDC		
CDO-D3	Diabetic Limb Amputation Rate		To Be Updated By SHCC's PDC	To Be Updated By SHCC's PDC		
CDO-D4	Ambulatory Care Sensitive (ACS) Admissions for Diabetes with Long Term Complications		To Be Updated By SHCC's PDC	To Be Updated By SHCC's PDC		
CDO-D5	Diabetes-Related Mortality Rate	Diabetes-related deaths per 100,000 persons	34.0 (Healthy Hawaii 2000 Goal)			

C. Community Specific Issues

According to the 1996 study entitled “Creating a Surveillance System for Diabetes in Hawai‘i”, approximately 52,000 people in Hawai‘i have some form of diabetes. At a prevalence rate of 43.8 per 1000 persons, diabetics account for nearly 4.4% of the state population. Compared to the national prevalence rate of 29.6 known diabetics per 1000, prevalence in Hawai‘i is 48% higher than the national rate.

Since age is a major risk factor for developing diabetes, the prevalence rate among our seniors (ages 65+) is more than 130 per 1000 persons, or triple the overall rate. By county, the prevalence rate among residents of the Big Island is nearly 50% higher than the statewide prevalence rate, whereas the prevalence rate among Kaua‘i’s people is 25% less. This appears to be related to the higher number of people of Hawaiian and Part-Hawaiian ancestry on the Big Island. Within each county, communities with higher prevalence rates are:

- Big Island North Kohala, Hamakua, Hilo, Puna, East Ka‘u
- Honolulu Wai‘anae, Kahuku to Ka‘a‘awa, Waimanalo
- Maui Wailuku, Kahului, East Central Maui, Hana, East Moloka‘i
- Kaua‘i South and West Kaua‘i

Again, ethnicity appears to be the determining factor here, as these communities have a larger share of people of Hawaiian and Part-Hawaiian ancestry.

Given that ethnicity is a major risk factor for developing the disease, the diabetes-related death toll shows a similar pattern. The mortality rate among Hawaiians and Part-Hawaiians is triple the statewide rate. The death rate for Hawaiians aged 45-64 is six times the statewide rate. As a matter of public policy, we clearly need to target a considerable level of treatment resources and preventive care programs to our Hawaiian and Part-Hawaiian communities.

D. Priorities

In order to reach the Health People 2000 goals for reducing the prevalence and mortality of diabetes, it is imperative that people in Hawai‘i with diabetes:

- (1) have their condition under personal control; and
- (2) be monitored by coordinated health care teams knowledgeable in the care of diabetes across the continuum of care.

Based on recommendations from American Diabetes Association and Kaiser Permanente Hawaii, the following are instrumental in achieving this effort:

1. Access. Access to quality treatment is important. People with diabetes need affordable health care. Medicare and Medicaid, as well as many private health care providers that follow their lead do not offer comprehensive coverage of the necessary supplies, services and education. The following changes are needed: prohibit pre-existing condition exclusions; provide coverage for prescription drugs and insulin, diabetes-related supplies, equipment and education; and provide a mandate for community rating.

2. Health Care Team Education. Health care team education is vital. Because people with diabetes have a multi-system chronic disease, they are best monitored and

managed by highly skilled health care professionals trained with the latest information on diabetes to help ensure early detection and appropriate treatment of the serious complications of the disease. A team approach to treating and monitoring this disease serves the best interests of the patient.

Current management of diabetes is inconsistent in the diagnosis, treatment, and follow-up amongst different physicians and other providers. This heterogeneous approach should be organized into a statewide state of the art chronic disease management system that involves screening, enrollment, treatment and monitoring.

- **Screening** - identify undiagnosed diabetics (early detection).
- **Enrollment** – placing a patient with the diagnosis of diabetes into a long-term relationship with a primary care provider (PCP).
- **Treatment** – the adoption of Staged Diabetes Management, a program developed at the International Diabetes Center in Minneapolis. It contains a stepwise algorithmic approach to achieve normoglycemia with specific time frames for follow-up and dosage adjustment. It will provide all PCPs and other providers with a common foundation for managing the disease.
- **Monitoring** – develop a computer-based registry of all diabetic patients and monitor outcomes.

In recognition of both the need for and feasibility of a statewide diabetes surveillance system in Hawai'i, the Hawaii Diabetes Data Network (HDDN) is in the process of assembling an unduplicated case level diabetes registry representing at least 85% of the state's population. Their next steps include, analysis of economic burden of diabetes, medical utilization patterns of diabetics and complication rates in this population.

3. Patient Education. Patient education is critical. People with diabetes can reduce their risk for complications if they are educated about their disease, learn and practice the skills necessary to better control their blood glucose levels, and receive regular checkups from their health care team.

4. Control of Blood Glucose Levels. People with diabetes, with the help of their health care providers, should set goals for control of blood glucose levels, as close to the normal range as is possible for them.

References

1. *Diabetes Facts*, American Diabetes Association.
2. "Creating A Surveillance System for Diabetes in Hawai'i", Report to the Hawaii State Diabetes Control Program, January 1996, Gertraud Maskarinec, MD, MPH.
3. *Hawaii Diabetes Data Network Final Report 1/30/98*, Pacific Health Research Institute.
4. Diabetes on Track Team, Kaiser Permanente Medical Care Program – Hawaii.

• Part 2. Asthma

A. Overview

In the United States, asthma affects an estimated 14.6 million persons. Asthma is the sixth-raking chronic condition in the nation and the leading serious chronic illness of children in the U.S., affecting an estimated 4.8 million children. People with asthma collectively have more than 100 million days of restricted activity, 470,000 hospitalizations annually and more than 5,000 people die of asthma annually. As in our nation, asthma is a major concern in Hawai'i. Based on data from the 1996 Hawai'i Health Surveillance Survey, 8.8 percent of Hawai'i residents have asthma.

Asthma is the Greek word for panting. A person having an asthmatic attack is literally panting for breath. Asthma is a condition that causes inflammation and obstruction of the airways. The muscles surrounding the air tubes (bronchial tubes) of the lungs go into spasm, the mucous lining swells, and secretions build up, making breathing quite difficult. Asthma usually occurs as "attacks" or "episodes." During an attack, the person may make a wheezing or whistling sound while breathing, cough a great deal, or spit up mucus. A chronic dry cough may be the only symptom of a mild asthma.

Asthma usually develops in childhood but may also begin later in life. The first episode often follows a cold or the flu. It is more common in children who are exposed to cigarette smoke in the home. Many children outgrow asthma as they get older but will still be at risk for it in adulthood. Most children and adults can control their asthma by avoiding triggers that cause attacks and using medications to manage symptoms. Severe attacks can usually be treated with inhaled or injected medications.

Many things can trigger asthma, including allergens, such as dust mites, pollen, mold, and animal dander. In general, infections are the most common triggers of asthma. Other triggers include exercise; cold air; cigarette or wood smoke; changes in weather; colds or the flu; chemical vapors from household or workplace products; analgesics (especially aspirin); food preservatives and dyes; sulfites in red wines, beers, and dried fruits; and emotional stress.

The following table identifies the four steps in asthma severity (National Institutes of Health):

Clinical Features Before Treatment	Symptoms	Nighttime Symptoms	Lung Function
STEP 1 Mild Intermittent	Symptoms ≤ 2 times a week. Asymptomatic and normal PEF between exacerbations. Exacerbations brief (from a few hours to a few days); intensity may vary.	≤ 2 times a month	FEV ₁ or PEF $\geq 80\%$ predicted PEF variability $< 20\%$
STEP 2 Mild Persistent	Symptoms > 2 times a week but < 1 time a day. Exacerbations may affect activity.	> 2 times a month	FEV ₁ or PEF $\geq 80\%$ predicted PEF variability 20-30%
STEP 3 Moderate Persistent	Daily symptoms. Daily use of inhaled short-acting beta ₂ -agonist. Exacerbations affect activity. Exacerbations ≥ 2 times a week; may last days.	> 1 time a week	FEV ₁ or PEF $> 60\%$ $\leq 80\%$ predicted PEF variability $> 30\%$
STEP 4 Severe Persistent	Continual symptoms. Limited physical activity. Frequent exacerbations.	Frequent	FEV ₁ or PEF $\leq 60\%$ predicted PEF variability $> 30\%$

Asthma entails an estimated annual economic cost to our nation in direct health care alone, of \$9.8 billion; indirect costs (e.g., lost productivity) add another \$2.8 billion for a total of \$12.6 billion. Among the ten most prevalent conditions, it ranks third in causing limitation of activity.

B. Measures/Indicators

1. Process Measures

The matrix below identifies key process measures and indicators that are pertinent to achieving the Hawai'i's Health People 2000 goals for reducing the number of asthma patients experiencing activity limitations and asthma morbidity.

Measure Number	Monitor	Definition	Guideline	Hawai'i Experience	Guideline/ Hawai'i Experience Source	Cross-Reference
CDP-A1	Number of Asthma Screening Programs		To Be Updated By SHCC's PDC	To Be Updated By SHCC's PDC		<i>Maternal, Infant and Child Health</i>
CDP-A2	Spirometry test results		To Be Updated By SHCC's PDC	To Be Updated By SHCC's PDC		
CDP-A3	Percent of Asthma Patients Who Have Had Appropriate Physician Contact		To Be Updated By SHCC's PDC	To Be Updated By SHCC's PDC	NCQA test measure	<i>Maternal, Infant and Child Health,</i>
CDP-A4	Number of asthmatics enrolled in patient education or management programs		To Be Updated By SHCC's PDC	To Be Updated By SHCC's PDC		<i>Maternal, Infant and Child Health, Behavioral Health</i>

2. Outcome Measures

The matrix below identifies key outcome measures and indicators that are pertinent to achieving the Hawai'i's Health People 2000 goals for reducing the number of asthma patients experiencing activity limitations and asthma morbidity.

Measure Number	Monitor	Definition	Guideline	Hawai'i Experience	Guideline/ Hawai'i Experience Source	Cross-Reference
CDO-A1	Asthma Prevalence Rate	Number of Asthmatics per 1000 persons	56.1 (1994)	87.7 (1996)	American Lung Association/DOH Office of Health Status Monitoring	<i>Maternal, Infant and Child Health</i>
CDO-A2	Asthma-Related Mortality Rate	Asthma-related deaths per 100,000 persons	1.5 (1994)	2.1 (1994)	American Lung Association/DOH Office of Health Status Monitoring	
CDO-A3	Asthma-Related ER Visits		To Be Updated By SHCC's PDC	To Be Updated By SHCC's PDC		
CDO-A4	Asthma-Related Inpatient Admissions Rate		160/100,000 Healthy Hawaii 2000 Goal	To Be Updated By SHCC's PDC		
CDO-A5	Ambulatory Care Sensitive (ACS) Admissions for Pediatric Asthma		To Be Updated By SHCC's PDC	To Be Updated By SHCC's PDC		<i>Maternal, Infant and Child Health</i>
CDO-A6	Ambulatory Care Sensitive (ACS) Admissions for Adult Asthma		To Be Updated By SHCC's PDC	To Be Updated By SHCC's PDC		

Measure Number	Monitor	Definition	Guideline	Hawai'i Experience	Guideline/ Hawai'i Experience Source	Cross-Reference
CDO-A7	Change In Population Severity		To Be Updated By SHCC's PDC	To Be Updated By SHCC's PDC		
CDO-A8	Change In Anti-Inflammatory To Beta-Agonist Ratio		To Be Updated By SHCC's PDC	To Be Updated By SHCC's PDC		

C. Community Specific Issues

According to the 1996 Health Surveillance Survey (a sample survey conducted statewide throughout the year by the Hawai'i Health Surveillance Program), approximately 100,700 people in Hawai'i have some form of asthma. At a prevalence rate of 87.7 per 1,000 persons, asthmatics account for nearly 8.8% of the state population.

Asthma is more prevalent in those 17 years old and younger. 39% of Hawai'i residents that have asthma are 17 years or younger. Hawai'i residents ages 15-17 years have the highest prevalence rate of 146.7 per 1,000 persons. This is 67% higher than the rate for all ages. Only about a quarter of the children with asthma become symptom-free when their airways reach adult size; for the rest, the condition is a lifelong ordeal. The condition persists beyond childhood in 85% of women and in 72% of men. Bronchial asthma is the number one cause of emergency room visits for children in Hawai'i.

Hawaiians and Part-Hawaiians have the highest prevalence rates of asthma. Their rate per 1,000 persons is 38% higher than the statewide rate. Asthma mortality varies markedly among ethnic groups; however, Hawaiians and Part-Hawaiians and Filipinos have the highest rates.

The distribution of prevalence rates of asthma by region shows the residents of Kaua'i experiencing the highest rates per 1,000 persons (113.0) and the residents of Honolulu experiencing the lowest (83.6).

D. Priorities

In order to reach the Health People 2000 goals for reducing the prevalence and morbidity of asthma, a concerted effort by the community, the health care providers, and the patient is needed.

1. Environmental Control Measures. Environmental control measures are needed to avoid or eliminate factors that precipitate asthma symptoms or exacerbation.

- Reduce to zero the emissions of air pollutants above permit levels.
- Explore improved extermination measures (to reduce cockroach allergen).
- Reduce exposure to environmental tobacco smoke.

2. Coordinated Health Care Team. Hawaii residents with asthma need to have their condition monitored by a coordinated health care team knowledgeable in the care of asthma across the continuum care. Health care providers need to provide the resources their asthma patients need, such as a coordinated asthma care management program (including a written asthma treatment plan) that will:

- Prevent chronic and troublesome symptoms
- Maintain (near) "normal" pulmonary function
- Maintain normal activity levels (including exercise and other physical activity)
- Prevent recurrent exacerbations of asthma and minimize the need for emergency department visits or hospitalizations
- Provide optimal pharmacotherapy with minimal or no adverse effects
- Meet patients' and families' expectations of and satisfaction with asthma care

3. Patient Education. An asthma patient needs to be knowledgeable about his/her chronic condition. Culturally sensitive patient education is essential. An educated patient can participate in self-management and is more likely to adhere to treatment programs. Patient education programs should have the following key educational messages:

- Basic facts about asthma – inflammatory nature of the disease.
- Role of medication – importance of long-term control and facts on steroid-based medications in inhalers.
- Self-management skills – inhalers, spacers, symptoms, peak flow monitoring for early warning signs of an exacerbation.
- Environmental controls (e.g., education on dust mites).
- When and how to take action against exacerbations.
- Jointly develop treatment goals – To encourage an active partnership, develop a written daily self-management plan and an action plan for exacerbations with the patient.
- Encourage adherence by promoting open communication, individualizing, re-viewing, and adjusting plans as needed; assessing patient perceptions of expectations and self efficacy; emphasizing goals and outcomes; and encouraging family involvement.

References

1. American Lung Association
2. Kaiser Permanente Care Management Institute
3. "Guidelines For the Diagnosis and Management of Asthma", National Institutes of Health, May 1997

Part 3. Alzheimer's Disease

A. Overview

Alzheimer's disease (AD) is the fourth leading cause of death in adults, after heart disease, cancer and stroke. AD is a progressive, degenerative disease that attacks the brain and results in impaired memory, thinking and behavior. Alzheimer's is the most common form of dementia. Dementia is a loss of intellectual function (thinking, remembering and reasoning) so severe that it interferes with an individual's daily functioning and can eventually result in death.

Symptoms of AD can include gradual memory loss, decline in the ability to perform routine tasks, disorientation to time, person and place, impairment of judgment, personality change, difficulty in learning, and loss of language and communication skills. The rate of progression in Alzheimer's patients varies from case to case. From the onset of symptoms, the life span of an Alzheimer patient can range anywhere from 3 to 20 or more years. The disease eventually leaves its victims unable to care for themselves.

AD affects approximately 4 million Americans; slightly more than half of these people receive care at home, while others are in many different health care institutions. Our nation is aging and unless prevention is found, 14 million people could have AD by 2010.

AD is a heavy economic burden on society. A recent study estimated that the cost of caring for one AD patient with severe cognitive impairments at home or in a nursing home, excluding indirect losses in productivity or wages, is more than \$47,000 a year. For a disease that can span from 2 to 20 years, the overall cost of AD to families and to society is staggering. The annual economic toll of AD in the United States in terms of health care expenses and lost wages of both patients and their caregivers is estimated at \$80 to \$100 billion.

The financial costs of AD do not provide a complete picture of the total burden. The emotional toll on patients and their families is profound. Clinical depression is prevalent in 20% of persons with AD and up to 50% of primary caregivers of AD patients develop significant psychological distress. Unless quality of life of both patients and caregivers is included, any economic assessment underestimates the true cost of the disease to society.

The National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association identified criteria that specify three levels of diagnostic certainty of AD: possible, probable, and definite.

- A diagnosis of **possible** AD is made when no other disease or disorder appears to be responsible for a person's dementia, but the onset or symptoms are not typical of AD. This diagnosis also may be made if the physician suspects AD, but the individual has another illness that might be responsible for the dementia.
- **Probable** AD requires that a patient have dementia and a history and pattern of symptoms consistent with those generally seen in AD. Also, other disorders that mimic AD must be excluded, which can be done from the history, examination, and laboratory tests.
- A diagnosis of **definite** AD is made when brain tissue from a person who was clinically diagnosed with AD is examined under a microscope, and the changes characteristic of AD are observed. This can be done using brain tissue obtained through a biopsy in a living person. Due to lack of a highly effective treatment and inability to reverse symptoms, most physicians believe biopsy is an inappropriate procedure for the routine diagnosis of AD. Therefore, a diagnosis of **definite** AD is usually made at autopsy.

The primary risk factors for AD are age and family history. The prevalence of the disease increased with the advancement in age. Scientists are exploring the role of genetics in the development of Alzheimer's, focusing on chromosome 19. (Rarer forms of the disease, which strike people in their 30s and 40s, often run within families and appear to be related to chromosome 1, chromosome 14, and chromosome 21.) Other possible risk factors for AD include, but as yet undefined, susceptibility genes, a previous head injury, female sex, and lower education level.

B. Measures/Indicators

1. Process Measures

The matrix below identifies key process measures and indicators that are pertinent to reducing the effects of the disease and prolonging health related quality life.

Measure Number	Monitor	Definition	Guideline	Hawai'i Experience	Guideline/ Hawai'i Experience Source	Cross-Reference
CDP-Z1	Cognitive Testing		To Be Updated By SHCC's DPC	To Be Updated By SHCC's PDC		
CDP-Z2	Behavioral Status		To Be Updated By SHCC's PDC	To Be Updated By SHCC's PDC		<i>Behavioral Health</i>
CDP-Z3	Functional Status		To Be Updated By SHCC's PDC	To Be Updated By SHCC's PDC		<i>Preventable Injuries and Violence</i>

2. Outcome Measures

The matrix below identifies key outcome measures and indicators that are pertinent to reducing the effects of the disease and prolonging health related quality life.

Measure Number	Monitor	Definition	Guideline	Hawai'i Experience	Guideline/ Hawai'i Experience Source	Cross-Reference
CDO-Z1	Alzheimer's prevalence rate		1 in 10 persons over age 65; half of those over age 85 (National)	17,000 in Hawai'i 14,000 on O'ahu	Alzheimer's Disease and Related Disorders Association	
CDO-Z2	Alzheimer's mortality rate		To Be Updated By SHCC's PDC	To Be Updated By SHCC's PDC		

C. Community Specific Issues

The Alzheimer's Disease and Related Disorders Association (ADRDA) estimates that 17,000 people in Hawai'i suffer from AD and of that 14,000 reside on the island of O'ahu alone. This estimate is based on the projections from Hawai'i 1990 census and national patterns which indicate that 1 in 10 persons over the age of 65 and 50% over the age of 85 have AD.

Only a small proportion of the estimated large number of people with AD is recognized as having it, making it a relatively under-diagnosed condition in the community. The difficulty in obtaining exact numbers is due to the fact that, at this time, there is no single clinical test to identify AD. In addition, myths surrounding the disease, differing cultural perceptions about the disease, and the "stigma" often attached to the disease (often associated with mental disorder) may contribute to the numbers who admit to suffering from AD.¹

As there are no firm numbers of statewide prevalence or incidence, nor any reliable demographic data (by geographic area, ethnicity, age, and sex), this type of information is needed.

D. Priorities

The following efforts are needed to reduce the effects of AD and prolong health related quality life.

1. Screening Programs and Public Education. AD is underreported and unrecognized because many patients do not seek evaluation and family members consider the loss of cognitive abilities a normal part of aging. Cognitive screening programs for the elderly and public education policies designed to increase awareness of early signs of AD are needed if interventions for individuals with potentially treatable AD are to be implemented.

2. Providers. Access to specialty care (i.e., neurologist, geriatrician, or geriatric psychiatrist) needs to be enhanced.

Physicians and other providers should be knowledgeable about the disease, how to diagnose the disorder correctly, and the effective treatment and management techniques.

There is no cure for AD presently available. The primary goals of treatment of patients with AD should be to improve the quality of life. Successful patient management should aim to minimize behavioral disturbances, maximize functioning and independence, and foster a safe and secure environment. The following principles are instrumental in achieving this effort²:

- Schedule regular patient surveillance and health maintenance visits every 3 to 6 months.
- Work closely with family and caregivers.
- Establish programs to improve patient behavior and mood.
- Encourage caregivers to modify the environment.
- Warn families of the hazards of wandering and driving.

3. Community Support Services. The community needs to continue providing available sources of assistance that will maximize AD patients' independent living and functioning. Examples of these are:

- Adult day care/Alzheimer's-specific day care
- Respite care
- Skilled nursing care provided by home health agencies
- Meals-on-wheels (food service for the homebound)
- Safe Return (ADRDA program to help locate people with AD)

4. Patient and Family Caregiver Support Groups and Counseling. Education, counseling and support will help patients and caregivers cope with feelings of anger, frustration, guilt, depression, etc.

5. Long Term Care. More cost-effective chronic care programs need to be available for the increasing number of people with AD.

6. Research. Future research should aim to improve diagnostic and therapeutic effectiveness.²

References

1. Alzheimer's Disease and Related Disorders Association, Inc. (ADRDA)
2. "Diagnosis and Treatment of Alzheimer Disease and Related Disorders", JAMA, October 22/29, 1997 – Vol. 278, No.16, pages 1363-1370.